

# COMMUNICATING TOGETHER

AS ABILITIES CHANGE

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Theme: Clinical Issues over the Years



For each of our last three issues, we decided to do a retrospective of the major sections that **Communicating Together** has addressed over the past eighteen years of its publication. In this issue, Tracy Shepherd and Colleen McGaffey discuss the clinical issues that have been raised during those years in the area of *Teaching and Learning* and Paul Marshall discusses *Paul's Place* since its inception. In the next issue, Nola Millin aided by Paul Marshall will do a similar retrospective for *consumer issues* and Geb Verburg will look back on the many topics he has discussed since **Communicating Together** began. In the final issue, Shirley McNaughton will review issues related to language, literacy and symbols and Peter Lindsay will explore how *Technology* has changed over the past nearly two decades of publication.

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## Teaching and Learning over the Past Eighteen Years

TRACY SHEPHERD &  
COLLEEN MCGAFFEY

When asked to take on one of the final issues of **Communicating Together**, we felt sad that the publication was coming to an end as we currently know it. It has been an excellent read for so many years and it will be greatly missed in the field both by consumers and professionals. We gave this issue

a good crack but feel there are not enough pages to tell the story of how things have changed over the years on the *Teaching and Learning* and *Clinical* fronts. It was our task along with Paul Marshall to summarize this information in twenty-three pages. We wanted to get a flavour from as many past contributors as possible. We feel that the following pages represent how far we have come as a field. Surprising (at least to us) is that over all this time and with so much technological development, we are still finding the same human barriers and the same human successes. And time marches on.

There have been many individuals who have contributed to the AAC community and **Communicating Together**. This retrospective look at AAC would be lacking without them. Some have been able to write at this time and some have not. The most important contributors to the field have been the consumers. **Communicating Together** has always endeavoured to keep focused on the AAC consumer and his or her perspective.

We would like to applaud Shirley McNaughton. Few who are part the AAC community have not been touched by Shirley's warm and giving spirit and few could ever say "no" to her invitations to share. That is why we are here today at the keyboard with our thoughts flowing to fill the pages of one of the last issues of this excellent publication.

We thanks those who have been involved and who have contributed over the years. We are

afraid to begin naming you all for fear that we will miss many of you. We know you are out there making a difference in your communities. And we know — "If only there were a Barbara Rush in every community" — AAC would be as common as the word hello. Barbara has been a long-standing contributor in many ways and has shared her ideas with many of us in **Communicating Together**. Unfortunately, her current schedule would not allow for a contribution at this time. Thank you, Barbara, so much for your wisdom and commitment over the years.

And all the other people who never get mentioned, the consumers and the teachers and the parents, we know you are there and are doing great things and need to connect with each other. Maybe we need another means to connect, to remember that we all have similar issues and barriers, and to support each other to continue to make progress in AAC.

During the early years, **Communicating Together** had a regular column called "*Sharing Ideas with Nora*". In the feature article Nora Rothschild shares her ideas with us again in 2000. Nora has done a marvellous job of reviewing the previous columns and commenting on "that was then and this is now". We are grateful to have Nora compile and reflect on the issues facing AAC in the 1980's and today.

Victor Valentic is also one of our contributors. He grew up through the years of **Communicating Together** and has a first hand view of how things have changed at least for him over the last sev-



eral years. He shares with us the story of how he has managed his education and advocated for himself during this time.

In this issue, Judy Seligman-Wine from Israel was gracious enough to review her previous submissions over the years and share her thoughts on how things have changed from her perspective. She discusses Blissymbols and their use in Israel. She reflects on issues facing families today and those of the past. Thank you Judy for your ideas. They are always welcome and refreshing.

We thought it most fitting to include in this issue a poem which was published in the inaugural issue entitled "Today". This poem was beautifully done in Blissymbols. Enjoy it and enjoy this issue!

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The next issue of **Communicating Together** will be a retrospective of the clinical and consumer issues discussed over the past eighteen years. Nola Millin and Paul Marshall will be the issue editors. Geb Verburg will share the issue, reviewing the topics addressed by him in **Communicating Together** throughout the eighties and nineties.

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## Today

*This poem was translated into Blissymbols at Hamilton Participation House by residents Russell Cecchini and Treena Guy, assisted by staff member Margie Szilagyi.*

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|-----------------------|-------------------------------------------------|
| Ω)(                   |                                                 |
| ∠ ∅ ∠ ∠ < \ ∅ → Ω     | This is the beginning of a new day              |
| △ ∠ ⊥ ∠ ∅ ∅ ∥         | God has given me this day to use as I wish      |
| ⊥ ∠ ∠ ∅ ⊕ ∅ < ∅ ∠     | I can lose time or use it for a good purpose    |
| » \ ∅+! »             |                                                 |
| ∠ ? ⊥ ∠ ∠ + ∠ ∅       | But what I do with this day is important        |
| ∅ ∅                   |                                                 |
| ∠ ∠ ∠ ∅ ∅ < ⊥+        | Because I am exchanging a day of my life for it |
| ⊕ ∅ ∠                 |                                                 |
| ⊥ ∠ ∅ ∠ ∠ ∠ ∅         | I promise to myself that it will be             |
| ∅+! -! ∅!             | Good not bad                                    |
| + -! ∅ ⊕              | Gain not loss                                   |
| ↔ -! ∠ ↔              | Success not failure                             |
| » ∠ ∠ ∅ ⊕ ∅ ∅ ∅ ∠ ∠   | In order that I never regret                    |
| ∠ ∅ ∅ ∠ ∠ ∠ ∅ ∠ ∠ ∠ ∅ | The price I have paid for this day              |
|                       | Anonymous                                       |

Material from symbol users is reproduced essentially as submitted in order to reflect individual creativity and different styles of expression. Neither symbols nor usages are to be regarded as models for expression or instruction.

Although the combine strategy is frequently employed to arrive at new symbol expressions, the personal symbol creation is often not enclosed between combine indicators as required by BCI practice.



# Sharing Ideas with Nora —Then and Now

NORA ROTHSCILD



*Nora Rothschild*

*Nora Rothschild has been one of the true leaders in the field of AAC. Her many and varied contributions have nurtured the field and helped it grow from a child into at least its adolescence. Nora was one of the very first Blissymbolics Consultants. She was also the first President of ISAAC Canada and it seems that she has held every role in between. Nora has been in the forefront of bringing AAC to children and adults who need it, as well as to families and professionals. AAC exists as we know it today in no small measure because of Nora's tireless efforts both in Canada and internationally.*

**W**hen the editors of **Communicating Together** asked me to write about my views on how things have changed since I first wrote the "Sharing Ideas with Nora" articles in the early 1980's, I reviewed the articles and contem-

plated. It struck me that not much has changed about the basic concepts of Augmentative and Alternative Communication (AAC) - and yet most everything we now do has changed in one way or another over the past twenty years.

I remember Shirley McNaughton coaching Lynnette Norris, Penny Parnes and myself on how to describe our new jobs as Blissymbolics Consultants to community professionals in 1980. As we went out to communities we needed to introduce (and spell) the term "Augmentative and Alternative Communication" and then move on to show people how to implement it. Twenty years later, most of us are still teaching implementation although most people now recognize the term.

In those early days, we started solely with Blissymbols and slowly recognized that some of our students needed other strategies as well. We had few resources, no research and limited high tech options. Yet, many of our students learned to communicate their needs and ideas effectively for the first time. We learned from our students. Twenty years later we now have a body of research, a proliferation of resources, a range of technology options, and we still continue to learn from our students. What has remained similar over time:

In the inaugural issue, I was pleased to find that even in 1982 we were "interested first and foremost in meeting the communication needs of non-speaking individuals." Even in those early days, we began with the communi-

cation needs and skills of the individual. We believed that the primary goal of AAC use and intervention was for the individual to become a better communicator. We understood that communication needed to be functional: "Our ultimate goal, don't forget, is to help the child communicate." Our goal then as now, was for communication to be successful - not the learning of a specific representational system or a specific piece of technology.

Even in the good old days, we understood the need for "good" communication partners. Then, we as professionals usually became the "good" partners. Now, we are aware that all communication partners need to learn to be facilitative communicators. This has now become a large part of our interventions.

In those days, as now, technology options were viewed as "sexy". Now as before, it is not unusual for some people to focus on the technology as the magical solution. As I wrote in 1985: "Let us not forget the original goal."

Even though in 1983 the idea was still controversial, many of us were experimenting with mixing representational sets (using pictures from different sets) and using multi-modal communication. I went out on a limb when I suggested that professionals "may want to try using pictures from one of the many picture systems available," when Blissymbolics were too complex for an individual. Most of us now accept that communication can (and should) be multi-modal, using different representational sets and modes,



and mixing high and light tech. We now have a multiplicity of high tech options but light tech concepts remain essentially intact. There are now more identified ways to organize vocabulary but many of us still use the "Fitzgerald Key" (basically a left to right progression of vocabulary organized by grammatical categories paralleling English language syntax) to organize many light tech displays. Some things stand the test of time: it works, it's efficient and effective.

In the early days, we knew that communication was needed for many different reasons — to make needs and wants known, for learning, for sharing, and to have fun. Now we are fortunate to have more research and some frameworks to assist us in helping consumers become effective, efficient and appropriate communicators. What follows is my summary of what I think have been the biggest changes I have seen over the past 20 years.

### **Role of Consumer and Family**

In the 1980's the belief was that we as professionals "knew" what was best for a consumer and we would be very "helpful" in making our well-meaning ideas happen. There were many workshops and conferences "for professionals only". In hindsight, it was really a type of segregation where professionals would be assured of knowing more because the information was channelled in their direction. We took pride in "talking on behalf of our clients". Over the years, we have seen many changes in the role of the professional.

It took many of us a while to realize that the most important things about AAC, we have learned from consumers. With these realizations came a shift

away from the "expert" or "medical" model to family-centred and social models. With this philosophical shift came the understanding that parents really do know their child best, that more mature consumers know their own needs, and that we as professionals need to trust them and allow them to take the lead.

Over the years, most professionals have acknowledged the need for a more empowering role for consumers. The Americans with Disabilities Act (ADA), the Pittsburgh Employment Conference (PEC), and other consumer-centered initiatives such as the upcoming Canadian Independence, Community and Empowerment (ICE) Conference have

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**"We were interested first and foremost in meeting the communication needs of non-speaking individuals."**

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fostered this change in worldview. It is a positive step forward that in the year 2000, 40% of the International Society of Augmentative and Alternative Communication's (ISAAC) Board of Directors are individuals who use AAC. Additionally it is now a requirement that each ISAAC Committee is required to have at least one member who is a consumer who uses AAC. In spite of these positive steps, we are still learning about the true meaning of empowerment and have discovered and that it doesn't just miraculously happen.

### **The role of advocacy**

We used to see ourselves as professionals who of course, kept

a "professional" relationship with our clients, and focused on our specific mandate for communication. Now it's not unusual to see professionals and consumers getting together to advocate for the rights of people with all kinds of disabilities e.g., ADA, Ontarians with Disabilities Act (ODA), and Augmentative Communication and Empowerment Support Group (ACES) at Temple University. People with disabilities have become more effective advocates on all levels — on a personal level as well as at the government level.

That individuals who use Augmentative and Alternative Communication have assumed the role of self-advocate is largely due to the fact that they now have a voice. They can now articulate their own issues. When the field of Augmentative and Alternative Communication began, many of the children we worked with had no effective way to communicate even basic needs. Now adults, they use their AAC systems to advocate for change on individual and systemic levels.

Parents these days also tend to accept their role more readily than in earlier days. I like to think that perhaps when we as professionals shifted from being the experts to working in partnership with parents, it helped to create this positive change. Whatever the reason, it does seem to be a significant change.

### **Inclusion**

In the 1980's most students attended segregated classes with dedicated staff who would remain with them for many years. They often had the interest, motivation, time and energy to gain expertise in the area of Augmentative and Alternative Communication. Most students are now spending much



of their time mainstreamed into regular classrooms. While there are many outstanding teachers, most of these regular classroom teachers have neither the time nor the interest to learn more than necessary for the one year that they will be responsible for this individual's education.

In the "*participation model*," Beukelman and Mirenda were able to present a usable framework that many of us had intuitively understood to exist, but could not articulate. Now we all understand the need to identify and eliminate barriers to participation including the opportunity barriers of policies, attitudes, and knowledge as well as the access barriers including physical, sensory, communication, and social skills. This was a big change from the "*prerequisite model*" in vogue throughout most of the 1980's. In that model, individuals needed to demonstrate competency in specific skills before being able to move on to developmentally "higher level" skills.

The "*prerequisite model*" often ill-served those whose development was not normative. By placing the emphasis on participation, opportunities were opened up for individuals to develop more effective means of communication. Entirely new populations could be served.

Nowadays, many professionals routinely serve those who are non-speaking since most agencies now provide services based on the need to communicate rather than the aetiology of disability. Therefore, although in the 1980's we saw mainly individuals whose physical challenges affected their communication, many are now addressing the needs of other populations. A

number of these clients are teaching us that behaviour is a form of communication and that AAC can effectively be used to meet the needs of individuals who have challenging behaviours.

### High technology

In the early 1980's the Apple II personal computer epitomized "high tech." We used the few commercially available programs and a dedicated cause and effect software programme. The Adaptive Firmware Card allowed some alternate access. We used tape recorders with loop tapes, cables and switches to provide limited voice output and dreamed of the day when all of this would be available within a small switch. Some of us voiced our dreams of having a computer replicate the power of light tech displays. We dreamed and asked for changing computer screens to emulate the physical task of turning pages, as well as to reduce the cognitive load of memorizing large amounts of vocabulary. Today we take dynamic display systems for granted. We have progressed to having a wide range of Voice Output Communication Aids (VOCAs) as well as software for writing, alternate access and rate enhancement. We have many more options, there is greater ease in programming and we have seen a move away from dedicated communication devices to computer-based technologies.

However with these advances, there seems to be a trend toward technology-driven rather than needs-driven AAC services. Many people have a renewed faith that the technology will solve all. The belief is that it is indeed magical stuff, instead of seeing technology as just one more tool that may help in improving functional communi-

cation. With the proliferation of technologies, the temptation is stronger than ever to equate the provision of technology with the solution to each and every communication problem. It is easy to forget that communicative competence is more than just being operationally competent. Thus, we continue to grapple with how to use these powerful tools effectively. In most cases, basic communication skills still need to be taught and rehearsed. Even with technology, one still needs strategic, social and linguistic competencies to use the tools effectively.

### Service delivery

We used to do our assessment and then prescribe a program. Subsequently, we would spend lots of time with each client practising in private. We naturally became very good communication partners. It took us awhile to understand that this skill did not come naturally to most people – other professionals as well as family members: interaction strategies needed to be taught. Ironically, I find that although there are more resources, there seems to be less time put aside to implement program ideas and really teach effective language usage. Everybody these days seems to be a consultant!

Yes, there are more community-based interventions and services. Many clients have more integrated teams working with them in a more holistic way. Professionals from various fields now try to work together but the manner in which they attempt to collaborate remains an issue, regardless of whether the team is officially multi, inter or trans-disciplinary in its constitution.



Collaboration is a buzzword that agencies as well as professionals know they want to achieve. There is now the understanding that collaboration is better than doing things independently. Many professionals are now trying to collaborate with clients and their families. However, most professionals still struggle to embody the notion of “collaborative consultation” in a meaningful way. The struggle notwithstanding, the efforts at partnership are starting to have significant positive impacts on the services we provide.

### **Emphasis on Measuring Outcomes**

The emphasis on measuring outcomes arrived more recently with changes in the economic climate. External forces have compelled us to look carefully at what we are doing and to become more accountable. This has moved us to focus on setting clear, measurable, client-focused, functional goals with a need to demonstrate change.

### **Research**

We now have a significant body of research thanks to the advent of postgraduate programmes dedicated to AAC and the development and growth of ISAAC’s AAC Journal for ensuring easy sharing of the research with the AAC community. The research touches most aspects of AAC, providing consumers and clinicians with better ideas and usually more questions. Although the research began with a few isolated clinicians and researchers, it has now blossomed to include many more collaborative efforts between not only clinicians and researchers, but more recently,

acknowledging the important role of consumers in research.

Through the research, we have learned about frameworks for understanding and teaching the processes. We have learned about the communication partner’s important role. Thanks to Janice Light and her colleagues, we now know that we are analysing operational versus social, strategic or linguistic competencies. Vocabulary selection for individuals using AAC has changed in many ways as well thanks to much of the work initiated by David Beukelman. More recently, research focus has shifted from “aided and unaided” symbol use and vocabulary analysis to the pragmatic use of communication.

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**“The world now recognizes individuals who use AAC to communicate as authors, artists, film stars, and scientists.”**

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### **Terminology**

Even in those tasks where we still do things in similar ways, our terminology to describe it has changed. We are now PC (politically correct) talking about an “individual with a physical disability,” rather than the “physically disabled person”. We now refer to “AAC consumers” rather than “AAC users”. Rather than patients, we now tend to use terms such as clients, consumers, students, and individuals. Many of us now describe individuals who use AAC as “non-speaking” rather than “non-vocal” — to reflect that most individuals really do have a lot of vocalizations that are useful,

but they cannot speak to communicate functionally with various partners.

We now “engineer” the environment rather than setting it up to create more opportunities. We now identify partner strategies rather than just giving tips for general language stimulation. In addition to using pictures for displays, we now take for granted that we also use “visual strategies” to support individuals.

Most professionals now aim to be “client and family-centered” with a view to improving the “Quality of Life” of an individual and the family. These and many other terms have evolved to reflect our changing philosophies and our growing understanding of the communication process.

### **Information Technology**

The availability and access of Information Technology used to be the exclusive domain of engineers or highly specialized technologists. Now it seems to be in common use everywhere. Our very dependence on voice mail, email and the Internet provides ready evidence of this dramatic increase in the popularization of technologies in AAC over the past twenty years. We all have easy access to virtually limitless information. This proliferation of information technology has also benefited the AAC community.

The field of AAC now has its own modern-day “AAC Bible” — the book, *Augmentative and Alternative Communication*, by David Beukelman and Pat Mirenda. There are of course many other excellent textbooks used by professionals and families alike. In addition we finally have a vast array of functional resource



books such as Goossens', Crain and Elder's *Engineering Environments* series and Peggy Locke's *Making Connections* book. These are just a few examples of the many workbooks that now provide everyone with great ideas without each one of us needing to reinvent the wheel the way we used to. Hot off the press is ISAAC's new book of art, poetry and prose from over 150 consumer submissions in 12 countries. We can access the latest in research in the ISAAC-sponsored journal, *Augmentative and Alternative Communication*, which in turn, impacts our daily practice. In addition, until this final volume, our young field had at least two excellent magazines: **Communicating Together** and **Augmentative Communication News**.

We now have post-graduate programmes at numerous universities specializing in AAC. The field has many conferences and is represented by Special Interest Groups within larger associations such as ASHA. Lastly we have the International Society of Augmentative and Alternative Communication (ISAAC) with all its international chapters, conferences, linkages, and publications. That's quite an accomplishment for a mere twenty years.

### Increase in Role Models

The world now recognizes individuals who use AAC to communicate as authors, artists, film stars, and scientists. Dr. Stephen Hawking had as much impact on the AAC community as he did on the scientific one. Tel-

evision shows regularly highlight individuals using computers and VOCAs. Movies such as *My Left Foot* and books by individuals who use AAC such as Ruth Stankiewicz-Mercer's personal story: *I Raise My Eyes to Say 'Yes'* have exposed the public to AAC. These individuals have all helped to increase public awareness by being role models. The whole world is now more aware that there are options for people who need alternative ways to communicate.

In addition to being role models for society at large, there are now many individuals attending universities, working, spending their time on listserves such as Temple University's ACOLUG, sharing their experiences with audiences, or spending time working with younger people. They are mentors to the younger generation – role models helping to show the way. We are now beginning to see formal peer mentoring programs such as the Penn State AAC Mentor Project, and the ISAAC 2000 conference offered a special meeting chaired by mentors. Yet, some things are difficult to change....

For all the progress, some irritants remain, seemingly immutable:

- Am I the only one who still goes out and sees "eat, food and toilet" on a young child's wheelchair tray when what he really wants to say is "I want to play with the pup-

pet", "go outside" or tell you to "stop that!" Usually it is a child that is still in diapers and where eating is a big chore!

- In 1983 a frequently asked question was: "Why must he start so young? Would it not be better to wait until he is older and can concentrate better?" I think many of us still hear this same question. We still respond with the idea that "although a child may be unable to talk, he or she still has needs and ideas to express..."
- Another question we continue to hear is: "Will AAC interfere with speech development?" Although we have some research and clinical findings, it is still difficult to get the idea across to parents and persons new to the field, that AAC is an important adjunct to youngsters whose speech is very difficult to understand.

Looking back over twenty years I think Daniel Webster's quote remains an inspiration to those of us involved with improving communication skills. "If my possessions were taken from me with one exception, I would choose to keep the power of communication for by it I would soon regain all the rest. " The day-to-day plodding may be challenging, but we always need to keep the goal in mind.

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## On the Teaching Platform

TRACY SHEPHERD



There are so many issues to be dealt with from the *Teaching and Learning* section of the magazine. The main issues appearing over the years were service delivery models and integration. I will only begin to touch on these topics and other smatterings that we found interesting.

Margaret McCuaig of British Columbia, Canada, in the September 1985 issue of **Communicating Together** stated:

"I love my work because there is so much opportunity for creativity, always something new to discover".

That is the nature of AAC. It is always changing in so many ways. That is one of the reasons I love my work. Margaret and I share the same opinion as well. As she explains it:

"There is a great deal of job satisfaction working with

clients, families and clinicians in the field of non-verbal communication".

Shortly thereafter, in the June 1986 issue of **Communicating Together**, Clive Thursfield of the UK explained:

"Although our centre is known for technology, we don't consider ourselves as a technological centre. We think of ourselves as a people centre...One of our most important guidelines is people first, machines second".

It is so nice to read statements like these and see these principles being practised then and now.

Both of the above writers also mentioned the notion of the *Trans-disciplinary* approach to service delivery. In AAC, we aim to cross professional boundaries. I feel the sign of a good team is when nobody really knows each person's title. I am a speech language pathologist by training but I will tell you I have learned a thing or two about occupational therapy, education, and technology just from working with many amazingly talented individuals who are available to release their roles and work as a dynamic team. I love to hear an OT colleague talking about language and I have found myself making comments about positioning and access. I think this situation is more unique in AAC than it might be in a lot of other therapeutic specialties and I love it! I feel it really works.

### Collaborative Consultation

The concept of service delivery has been discussed in **Communi-**

**cating Together** many times over the years. One of the recurring themes in this area has been our role as consultants. We, as AAC professionals, tend to consult with other professionals, consumers and families. The result of these activities has been the emergence and wide implementation of a theory of collaborative consultation.

In the June 1990 issue of **Communicating Together**, Naomi Gibson discussed models of collaborative consultation and presented a check-list written by Anne Jordan Wilson. According to this check-list (Gibson, 1990a), a productive collaboration consultation relationship should have the following characteristics:

- The participants have a plan to share expertise interactively.
- There is an agreed upon goal.
- The plan is mutually agreed upon by all the participants.
- Each participant's contribution varies depending on the nature of the situation.
- There is a situational responsibility, depending on the nature of the problem, and the participants' knowledge.
- There is a demonstration of generic consulting skills.

Naomi Gibson also identified some of the key differences and beliefs around the consulting process (Gibson, 1990(b)):

- All stakeholders are involved in the process.
- Each participant's contributions are equally valued.
- The consulting process involves continuous feedback and change.



I think over the last ten years this model has been used and shaped to fit individual situations. I also think the role of consultants has many sides and many pros and cons. Some may question whether the role of the consultant is effective. One issue arising is that, in these days of limited and decreasing funds, everyone is starting to work as a consultant. Where does that leave the children needing the hands-on service? In many rural places that we serve there is an absence of community therapists, so we are either trying to consult to nobody or taking on a more active role. We also realize this places a bigger emphasis and responsibility on the family and caregivers. Depending on the situation this may not be a role they are able to fulfil without more support.

As consultants, the intervention is very client-driven. We often provide solutions along with a team and then leave saying call us if you need us. In all of our busy lives those calls sometimes don't come and it may become easier to just put the device or strategy in the closet and forget about it if it is not working. And so we talk about barriers to communication.

In a follow-up article in the September 1990 issue of **Communicating Together**, Steven Calculator described collaborative consultation as:

"An interactive process that enables people with diverse expertise to generate creative solutions to mutually defined problems".

I like the concept of generating creative solutions. This is the real hallmark of acting as a consultant, generating the solutions that will work in each case. We are not the

experts and we don't live the lives of the families and consumers daily so we don't *really* know what is best for them. We may have a lot of expertise to offer on the topic of communication but working through the barriers with the team and creating solutions becomes a much more productive endeavour.

Calculator lists the characteristics of the environments that children with severe communication disabilities should have, then goes on to discuss the barriers which will likely exist. Here are a few of them:

1. Difficulty getting all team members together.
2. Staff discontinuity.
3. Costs and funding.
4. Attitudinal barriers.
5. Policies and perspectives of government departments that conflict with collaborative consultation.
6. Lack of time, energy and opportunity to develop new skills.
7. Difficulty in reaching consensus about goals and agendas among members of the team.
8. Lack of commitment or resources to follow through on goals.
9. Hidden stakeholders who influence the process but don't participate fully.
10. Lack of opportunity for feedback to the team.
11. Expectations which build up during the waiting period.
12. Families seeing "more therapy" as better for their child.

As I read through these barriers, it became increasingly clear that although technological solutions continue to advance and open up new possible worlds for individuals with communication impairments, the essential barriers related to policy, attitudes, and knowledge remain. These are the barriers that are still the hardest to tackle.

## Integration vs segregation

Just a few years ago, in the December 1996 issue of **Communicating Together**, Barbara Rush looked retrospectively at various classroom practices and discussed the history of special education in Ontario. She focused on the pros and cons of the two primary competing models in education — integration and segregation. This article is still highly relevant today and I recommend having a look at it now and then as a reminder of where we were and where we are today. After working in the field for 30 years, Barbara comments:

"I do worry about the loneliness and isolation of some AAC communicators in large classrooms and a tendency to rely too heavily on technology in some settings...Computers are wonderful and I could not live without mine! However, communication is a social act and I don't believe that a computer or voice output device can ever replace down-on-the-floor, eyeball-to-eyeball contact with a student involved in learning and manipulating language symbols."

Barbara discusses what works and argues that in order to be successful, different children need to be taught language in different ways. These two approaches should not be treated as mutually exclusive alternatives. Maybe we need a combination of segregation and integration approaches depending on the specific needs of the child. Just today for example, I was at a team conference for a young girl who is entering the school system in which this very issue was brought up and hashed out from different angles. Which is the best system?



Another useful contribution to this debate was made by Faith Carlson in the March 1995 issue of **Communicating Together**. Faith's article was entitled "*How do you expect to get a job if you don't start in preschool?*" In answering her own question, Faith listed nine areas crucial to development:

1. A responsibility for self and others.
2. A sense of time.
3. Interests and desires that reach outside of self.
4. A sense of money, its worth and its use.
5. Skill basics that are potentially marketable.
6. An independent communication system.
7. Social sensitivity.
8. A sense of realistic optimism.
9. A sense of the community in which we live.

Education has come a long way in teaching kids who have a communication impairment. I worry sometimes that we are missing out on some very fundamental skills that these kids will need. I like Faith's list. We should share this with teachers to help give direction to what is important.

I will finish off this section with some thoughts on the topic from Steven Calculator in the May, 1984 issue of **Communicating Together**:

"I have rarely observed any significant differences in the efficiency, clarity or overall success with which nonspeakers convey messages after they have been provided with communication boards, as compared with their non-board methods of communication (vocalizations and gestures). This lack of differences is particularly evident in the

nonspeakers' spontaneous communicative efforts."

A colleague of mine reflects sentiments that are very similar to Steve's:

"A good communicator will learn to communicate in spite of the technology we give or don't give them."

These basic educational issues are essentially the same in the year 2000 as they were fifteen years ago when Calculator was writing about them. Technology has not been quite the panacea that people had hoped it would be. Fortunately people are flexible and innovative. Even with all the fancy technology in the world that is now available, people still find ways to use low-tech or no-tech to communicate with each other. As a matter of fact, in spite of all its success, technology has also masked many important issues. Barbara Rush wonders if we have not gotten lost in focusing on technology and missed teaching language and other essential communication issues. In most communities, who does the language teaching? Where is the teaching part going? I don't like to sound down on technology. I love it! I just like to keep things in perspective. Remember that it is all about people and communication first.

### **Educating the Professionals**

In reviewing the past two decades of teaching and learning articles in **Communicating Together**, one of the interesting issues that has frequently arisen is the issue of the kinds of education in AAC that professionals have received. We have seen lots of changes in this over the years. More recently, there has been a tremendous push to include con-

sumers in this education of professionals.

In the *inaugural* issue of **Communicating Together** (Fall, 1982), an interview with Linda Hicks Gleckel emphasized the central importance of education of professionals in the area of AAC and the relative lack of opportunities for professionals to receive such education. In this interview, Gleckel stated:

"A major problem that appears to exist at the present time is inadequate preparation in non-speech communication in higher-education and teacher-education programs. With the exception of few major universities where courses, seminars and/or research in AAC involve doctoral students, most special education and speech pathology programs fail to offer any courses that familiarize students with non-speech systems...Both Canada and the United States appear to be committed to the development of programs to facilitate the communication of non speaking persons. Although programs in higher education appear to be inadequate in preparing professionals in non-speech communication, teachers, speech pathologists and other professionals and parents are seeking expertise in this area through seminars and workshops. Right now, what we need to do is ensure that non-speaking people receive the help they need; and to do that I believe we need to educate professionals who will be working with this population. We also need to educate people in the community so that everyone will be more comfortable with non-speaking individuals."

Although there are still programs lacking in any comprehensive training in AAC, there has



been some improvement in this area over the years. Some universities offer AAC as an elective and not as a prerequisite course while others have full courses, internships and doctoral programs available in the area of AAC.

In spite of having no formal opportunities to take course work on the subject, there are lots of ways that those of us who have specialized in this area have learned about AAC. I can remember back (I hate to say it) about 10 years ago when I was a fresh new graduate with no formal training in AAC other than my clinical placements and independent study. I was petrified! Besides feeling utterly useless, I had to be an independent learner and seek out the opportunities to learn about the field to increase my confidence and competence. The opportunities have increased for new graduates and veterans in the field to expand their clinical expertise. Some of those opportunities include:

- *Conferences* — so many more available focusing on AAC or at least having AAC content
- *Professional associations* with special interest groups dedicated to AAC (i.e., ASHA and ISAAC)
- *Internet, Email, Listservers, Newsgroups* to help us talk to each other and obtain information more easily
- *Research Journals* with AAC content as well as the AAC journal itself
- *Text books* and other literature with functional applications and ideas
- *University courses* and seminars
- *Informal learning* from colleagues.

- In *Sharing Ideas with Nora* (Rothschild) in the March 1986 issue of **Communicating Together**, the need to share ideas was discussed. We now have so many ways to do this. The internet in particular has provided a valuable new medium for doing this.
- *Learning from doing* (trial and error — Come on, we all do it!)
- *Using vendors* to do training on new devices; while the theory stays the same, the tools continue to change and advance.

So there are many more opportunities for professionals to be educated and stay up-to-date. We are lucky that technology changes have helped in this development. Remember the old way to connect with other people in the field — “Confer”. I barely remember it but I don’t think it worked as well as all the newer ways we have to stay connected. (*Editorial Comment:* Yes it did. In fact, take it from one who used it extensively, it was away ahead of its time.)

### For the AAC User

One of the notable changes related to the education of professionals is that we seem to be learning from consumers more and more. This is so much more appropriate. As Nora Rothschild suggested in her article in this issue, we have a pretty good handle on the clinical aspects. That hasn’t changed all that much. We are doing a much better job at asking the consumer, “What are we doing right?” and “What needs to be changed?”. We are certainly not the experts and the way consumers have a louder voice in the field speaks to that reality. I per-

sonally would rather listen to a consumer’s perspective than hear how to download or is it wide-load (I get confused!). The technical aspects I could probably figure out. What will improve my clinical practice is understanding the impressions, feelings and needs of the augmented communicator.

There are several concrete ways consumers have made their presence known in the field. Being a part of the ISAAC board and other organizations is only one small part. Specifically, there are conferences and programs now run by and for augmented communicators and they are gracious enough to allow us clinicians and teachers to attend in hopes that we might learn something. A few of the programs I am talking about are outlined below:

### Augmentative Communication and Empowerment Supports (ACES):

This program was developed by Diane Bryen in Philadelphia at the Summer Institute, Temple University. The participants at the conference have a combination of physical and speech difficulties. Its primary purpose is to assist in developing a literal, social and political voice and the goal is to enhance the participants’ opportunity to live independently and to gain access to resources. This is done by providing augmentative communication technology, immersion training and ongoing support in the community.

Advocacy is a key with the following goals:

- to prevent, reduce, or eliminate depression
- to become a more enabled person
- to teach about basic civil rights



- to increase independent living, education and employment prospects
- to increase personal choice and control
- individuals are taught how to use, program and maintain their devices during the immersion phase.

Professionals, tutors and allies are taught to be partners and advocates in providing needed assistive technology, services and supports to people with significant physical and speech disabilities. Westpark Hospital in Toronto is considering expanding the ACES in Canada

### The Pittsburg Employment Conference (PEC)

This event is held annually in Pittsburgh with a new theme each year. Last year's theme for example was employment, marriage and sexuality. The conference is for individuals who use augmentative communication and provides them with a forum for discussing issues that are important to them. There is a town hall meeting during the conference at which only augmentative communication users can speak. From what I have heard (I have not attended yet), this is an amazing event to observe. It is also interesting to note that some individuals did not want others to facilitate their dialogue. This is a forum for them to be completely independent and the speaking people are the visitors. Although the majority of individuals used Liberators, the device used is not the focus of the conference.

This conference is a great example of real life communication. Colleagues who have attended explain that we, professionals, need to hear clients' dreams

and goals and this is an excellent opportunity to do so. I would love to go next year!

### Terminology

On the topic of advocacy, as I read through old articles, a thought comes to mind regarding the changing wave of terminology and what it is appropriate to call individuals who have disabilities.

Reading the old issues, I cringe at some of the descriptive terms used. The appropriate reference today is "people first". For example, I would be a user of AAC and not an AAC user, a child with cerebral palsy and not a CP child.

I quote Paul Marshall saying "Who am I — a consumer or a Paul?". As Hank Bersani describes it in his paper *From Social Clubs to Social Movement: Landmarks in the Development of the International Self Advocacy Movement*, there has been a conceptual reform. The larger advocacy movement began in Sweden 1965 and spread to the USA in 1973. There has been a conceptual reform and the term "*We are people first*" has developed along with this movement. The conceptual reform aims to eliminate stereotypes and offers new definitions. The claim is that "Mr." is not an acceptable term and that it really means "Mighty Remarkable". The language has changed to include good use of rhetoric — "We speak for ourselves" and "Nothing about me without me". I was fortunate enough to hear a collection of speakers (including consumers of course) discussing advocacy at ISAAC 1998 in Dublin. This type of discussion helps to keep us in check and to remember that we no longer function in a medical model in which we work "on" patients.

Consumers work with us to come up with solutions that will best meet their individual needs. Thank goodness we have arrived in a place where we realize the true partnership we have with our clients and students.

§

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### Chase your Dreams — Guidelines for Getting a Good Education

VICTOR VALENTIC



*Victor Valentic has been a generous contributor to **Communicating Together** since 1991. AAC has had a personal impact on his life. We thank him for sharing his experiences and his insight with our readers. His determination encourages all of us to face the challenges of life and grasp opportunities for advocacy that will benefit all people.*

I would like to share with you how I managed my education during college. Throughout this discussion I will highlight how every individual with disabilities deserves a comprehensive education compatible with their individual capabilities.

As a result of Reyes Syndrome, I now have cerebral palsy which has taken away my ability to speak. I also have difficulty with fine and gross motor movements. In Hamilton, Ontario, Canada, where I still live, there is a community college named Mohawk College.

I went through regular schools my entire life. My parents insisted that I have the same educational opportunity as all children and be exposed to the same knowledge and curriculum that all children are exposed to. During high school I was identified, as a special needs student. I had agreed to have standardized psychological testing done by the school system, so that an Individual Pupil Plan could be developed for me. The advantage of being identified as a special needs student was that I was allowed to take 3 rather than 4 courses per semester. I also had access to a special education resource teacher.

It took me five years to complete high school. After completing high school in a semestered system, I applied to Mohawk College, in Hamilton. I met the stated requirements and was accepted. I enrolled in a three year Co-operative Computer Systems Technology Course. However, it took me seven years to complete my courses and graduate. While at Mohawk College, I collaborated with the Special Needs Department to arrange accommodations for my education.

In my first several months at Mohawk College, the Special Needs Department played a role in helping me to become acquainted with the college. I soon learned that it was simpler for me to deal directly with my instructors. I also felt that it was important for me to cope as independently as possible in order to develop the life skills that I would need after graduation. I believe that it is important to be offered control of one's situation and to accept responsibility for it.

Prior to my attending Mohawk College, the special needs students were not allowed to take reduced course load. Over time, Mohawk developed a Special Needs Policy, which dealt with course load issues. In consultation with my professors, we decided that I should take three or four subjects per semester because the full course load would be too much for me. In my opinion every disabled student should only be required to take three or four subjects per semester!

In the early years at Mohawk, I was involved in Disability Awareness Week activities. The Mohawk Student Association and the Special Needs Department organized this event. The objective of this was to raise the awareness of the student body at Mohawk regarding disabilities and disabled students at the college.

Advocacy issues became my passion. I involved myself with improving the wheelchair accessibility at the front entrance of the college. Mohawk College has a



long driveway to the front door. The buses for persons with disabilities have to drop off and pick up their clients at this door.

However, some people thought the front area was a parking area. I spoke to the Physical Plant Department, Special Needs Department, and the Security Office. As a result of this, they put up "No Parking" signs and added a security patrol to the front entrance.

With the assistance of a friend, I also called the city of Hamilton and complained about the lack of curb cuts on the sidewalks outside of the college. I must have a lot of influence, because the city actually followed through and did the curb cuts! The sidewalk accessibility was not great on campus either. I submitted a proposal to the Physical Plant Department to change the sidewalks. My proposal was accepted and the changes were made. I won an award for this proposal. If you want action, you have to take action because, as everyone knows, the wheel that squeaks, gets the grease.

I have used many adaptive devices. When I started college I was using an IBM compatible laptop computer with a speech synthesizer. I was also using an Epson with a speech pack for face-to-face communication. Then I made a choice to get a Liberator instead of using both a laptop computer and the Epson.

Obviously, all this equipment required a considerable amount of funding. I was fortunate to be able to access funding from the Assistive Devices Program of the Ministry of Health, Vocational Rehabilitation Services. During my fifth year I also received a

college scholarship from Amity-Goodwill.

I relished the chance to participate in the class group discussions. This gave me a chance to show what I could contribute and also gave my fellow students and my teachers a chance to pay attention to how I used my Liberator. Perhaps most importantly, they had to listen to what I had to say.

---

**"Advocacy issues became my passion . . . . If you want action, you have to take action"**

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I lead a panel discussion for one of my system classes. This opportunity did a lot to enhance the perceptions that my fellow students and my teachers had of me. The experience was made possible by the technology as well as by having a teacher who could see my abilities and not let my disabilities define what I could do.

I found that some of my friends were excellent instructors and shared their time and knowledge with me. This allowed a bond and friendship to develop. My friends have taken me out to lunch, they visit me at my home, I call them on my speakerphone, and we write through email. There were also times when they came to me as the expert and showed me that they saw me as a competitive student in the program.

It seemed that this was not the case with the Special Needs

Department at the college. My special needs counsellor typically simplified her speech when talking to me as if I wouldn't understand normal conversation. I never felt that she really took the time to know my capabilities or understand me as a person. Most of my teachers and peers did a better job at this than the Special Needs Department.

Most of my teachers have been quite good. They were helpful and quite intuitive when interacting with me. Communication was not always quick or easy but they were patient and eventually I felt that they understood what I was trying to express.

One of the positive things about being involved with the Special Needs Department was that my test schedule was adapted to make it manageable for me. I completed my tests in a separate room and I was given 50% more time to complete them. The Special Needs Department also arranged for a reader, who also acted as a scribe for tests, as well as helped me use the stationary computer.

In December 1997 when I was doing a final exam for one of my courses, the special needs department cut me off after 4 hours. I needed one hour more to complete the exam. The special needs department refused to call my teacher to get his approval to give me another hour. I felt that they should have done this in their role as a support to me. Thank God, I talked to my teacher before the exam and he said that if I passed my exam then I would pass the course. I passed my exam and passed my course. I would recommend that students prepare ahead for exams



and negotiate with their teachers that they can request additional time to complete an exam if necessary.

I feel that my educational experience has been a positive one. However, this has taken a great deal of determination from my parents and me. I still question whether involving special education at all levels was beneficial in my educational accomplishment. The things that have helped me most have been:

- ramps for my wheelchair,
- doors that open automatically, elevators,

- washrooms that are accessible,
- a quiet room for my exams, and
- the use of my special equipment.

Although I obviously have some mixed feelings about special education, overall, I feel that it is essential for students with disabilities to have a resource person with whom they can discuss course requirements and equipment needs. However, care must be taken not to create a co-dependent situation where the student is too reliant on assistance and the

support workers want the student to be dependent.

Getting a college education has been very important to me, as it will better my chances in getting a job anywhere in the world.

In summary, my guidelines for getting a good education would be:

1. Take your schooling slowly
2. Choose your friends carefully
3. Talk with your teachers before you write your tests
4. Use special needs resources wisely. Do not let others take control over your education.

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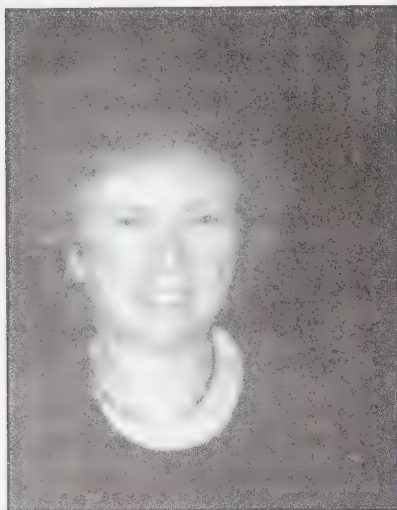
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## Decisions and Commitments: Then and Now

JUDY SELIGMAN-WINE, Ed.D.



*We welcome Judy Seligman-Wine's contribution to **Communicating Together** once again. She has been instrumental in the development of AAC as a field internationally. As one of the first to teach Blissymbolics, she reminds us of the grassroots of AAC. With her broad experience, she shares first-hand how far we have come.*

In recent years, I have had frequent occasion to reflect upon the decision made back in the 1970's with regard to the use of Blissymbols for non-speaking persons in Israel. At that time, after much deliberation and in conjunction with the international Blissymbol community, the decision was made to reverse the order in which compound Blissymbols were written, in order to be consistent with written Hebrew, the national language of Israel. The opportunity afforded to me now by **Communicating Together** to comment upon my past contributions to this excellent magazine allows me to share these reflections with others.

In February, 1984, I wrote an article on "*The Development of Blissymbol Stamps in Hebrew*" (Seligman-Wine, 1984). In that article, I outlined some of the issues that were encountered when attempting to apply Blissymbols as a form of AAC in a linguistic and cultural milieu that varied greatly from the original English language background in which they were first conceptualized (this, in spite of the fact that Charles Bliss' intent was to develop a graphic symbol system which was non-language based). A major issue was that indicated above i.e. the linear direction in which compound Blissymbols should be written, given that the Hebrew language is written from right to left. The decision made at that time was that, in Israel, compound symbols

containing more than one component should be written from right to left. However the individual symbols within the compound symbol, with some minor exceptions (see article), should retain their original orientation. This seemed like a very prudent decision at the time. While the importance of visually perceiving the symbols in the same orientation as the written language for literacy and language considerations was recognized, care was taken to keep the system as close to the original as possible.

While we are still convinced of the validity and importance of this decision, there have been numerous times when we have wished it could have been otherwise, particularly with the advent of technology which was so far away from us and our considerations at that time. (See also the article "*International collaboration: SYNREL comes to Israel*", Seligman-Wine, 1988a). If we had not changed the direction of the writing of compound symbols, it would have been possible to adapt much of the Blissymbol software developed around the world for use in Israel, simply by changing the gloss above the symbol. And even if we had changed the linear direction which would have then necessitated the reversal of the software to a right-left orientation, if only we had written the symbols as mirror-images to their original counterparts, how much easier our lives would have been. As this was



not the case (and legitimately so), it necessitated the writing from scratch any Blissymbol software which we wished to use in Israel — a burden which we are carrying even to this day. Other issues mentioned in the article included the need for different vocabulary items to represent cultural, ethnic and religious concepts, the need for symbol synonyms e.g. winter in Israel is the season for rain rather than the season for snow, and the need for different grammatical constructs e.g. some words which are verbs in English are adjectives in Hebrew, etc. In reviewing these various issues, it becomes evident the extent to which they are relevant even today.

In September, 1999, a very productive Blissymbol International Panel Workshop was held in Cape Town, South Africa. For close to two weeks, 15 people from nine different countries worked on the development of new Blissymbols. Many of the issues encountered and discussed paralleled those issues raised in the article written 16 years ago. While the field has developed and we have moved on in so many ways, it is interesting to realize how many of the issues which we face are the same or similar to those with which we dealt in our infancy stage.

### Speech Output

In 1988 I reported on “A Blissymbol Bar Mitzvah” (Seligman-Wine, 1988b) held in Israel. The “sensational” item that rendered the occasion newsworthy both in Israel and abroad was the use of voice output within the Bar

Mitzvah ceremony. The 13-year-old boy was able to fulfil his obligation of becoming a ‘man’ within the Jewish religion by reciting out loud the prayers, blessings, and reading of the bible portion using synthetic speech. The software he used was developed and adapted for the occasion by Dr. John Eulenberg, Director of the Artificial Language Laboratory at Michigan State University, in the U.S. While this may not seem out of the ordinary for some of us today, it must be realized that in many parts of the world in which the dominant language is spoken by only a small number of people, and particularly if financial resources are limited, voice output is only but a dream, even today.

In Israel, where this exciting event took place thirteen years ago, synthesized speech has been a long time in coming. This is due to a profusion of factors, including the complexity of the Hebrew language, a very limited market, and the high cost of such development. Still today, AAC users in Israel are limited to the use of digitized speech output. This has some advantages, but certainly does not give the full range of expression which is possible with synthesized speech. In April, 2000, the first public lecture was given using Hebrew synthesized speech at an ISAAC-ISRAEL workshop. It was a very exciting and emotional event. The quality of the speech was good and it was, for the most part, intelligible. Even so, the software used is still being beta tested and is not yet available commercially. While we have moved forward from the day

of the Bar Mitzvah 13 years ago, we are still only on the way to the realization of a dream — that all voices will be heard!

### Involving Parents

In yet another article written at that same period of time (Seligman-Wine, 1987), I reported on several Blissymbol workshops which had been given in Israel specifically to and for parents. While parents had always been welcome participants in every workshop presented, the request came from parents for a course designed specifically for them. Details and observations regarding these workshops are available in the original article. In reviewing this article, I cannot help but marvel at the weight and responsibility which was placed on parents, and other family members, even at the beginning stages of the field of AAC. The success of an AAC intervention program rested largely on their shoulders — and still does! Yet the parameters have changed, or at least have been extended. In 1987, discussion centred largely on parental acceptance of AAC intervention and use of AAC in the home setting. Today this has been expanded to include advocating for the AAC user’s right to communicate, to receive services and equipment, to be included in regular classrooms, etc. Two years ago I organized a course to teach parents of children who communicate using AAC to advocate for their children (Seligman-Wine, 1998). The model for this course was based on the *Partners in Policy-Making* concept developed in the United



States (Goldman & Tachau, 1996; Zirpoli, Hancox, Wieck & Skarnulis, 1989; Zirpoli, Wieck, Hancox & Skarnulis, 1994). Unfortunately, AAC users themselves did not participate in the course held in Israel, as was done in the courses held in the United States.

### The Future

I see the field as constantly moving forward, building on past experiences. The next step in this progression must be the emphasis on self-advocacy, both locally and internationally. It is time for professionals and parents to let go, with the realization that there is a strong group of AAC users who can be depended upon to speak out and fight for themselves. This message came through at the ISAAC biennial conference held on Dublin in 1998. I had the good fortune to hear it again at the Pittsburgh Employment Conference which I attended in August, 1999. As I write these thoughts based on articles which I have published in the past, I am reminded of one of my recurring impressions. Much of what I wrote and advocated for in the 1970's and 1980's was referenced in Blissymbols as a means of com-

munication for persons with severe speech impairments. In the 1990's, the field broadened and the term of reference became AAC. It is true that a variety of graphic systems became available for use by AAC users, many of which demanded less on a variety of different parameters both from the professionals providing AAC services and from the AAC users. However, certainly in Israel, Blissymbols as a possible AAC tool was never totally abandoned in favour of these other "easier" systems. As a greater variety of graphic tools became available, it became possible to better identify the graphic tool(s) which would most closely meet the needs, abilities, and interests of each individual AAC user. For those AAC users today who communicate using Blissymbols, the possibilities for self-expression are endless, based both on the ever-expanding Blissymbol vocabulary made possible by the International Blissymbol Panel and by the users themselves, through the use of creativity and imagination in the combination of symbols to create new concepts. We did not throw out the baby with the bath water!

§

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## ComTog On-Line in 2001?

As we noted in the editorial, this is the last year for us to publish **Communicating Together**. Some of our readers wrote to say that we might want to continue with an on-line version. We shared those thoughts with Paul Marshall and Nola Millin secretly hoping that they would be intrigued by the idea of a solely internet magazine. They are cautiously considering a metamorphized electronic form of ComTog. Would there be interest in this publication? By potential readers? By potential contributors?

Paul and Nola await your reaction.

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### Reflections Over the Past Eighteen Years.

PAUL MARSHALL

**T**hey say that man can learn from his past if he is willing to look over his shoulder. Why is it that it is only when something is about to end that the human being seems to take the time to reflect? Could it be that something in us needs to view life as many circles of learning? Is there really a true end of anything or does an ending simply mean that something new is about to start? It seems when one door is shut, another one opens.

What got me thinking in this direction? As you know, this is the last year we will be publishing **Communicating Together**. I know we as editors and coeditors are sad to see the ending of this magazine. We hope that most of our readers feel the same. Down through the years, our magazine tried to share the issues head-on that faced the international AAC community. I joined the team in 1993 and always felt it was a great honour to be an Associate Editor. I would like to personally thank Shirley McNaughton and Peter Lindsay as the editors. Both of them have put in untold hours over the years. Bob McNaughton is also to be thanked for doing the mailing, which has been not a small task. Lastly to my co-Associate Editors — thanks for always being there with your support, your powerful writing styles and for your leadership which you freely gave to the AAC field. I believe we grew into a family which loved to discuss issues, and share our thoughts and ideas. It was because of this that we were able to produce the magazine we produced.

As I sit back and think about the expansion in the AAC field since the

70's, I am truly amazed. The 70's were a time of blooming of all kinds of new ideas that impacted greatly on the AAC community. As the first AAC system, Blissymbolics made a large impact on many consumers. I wouldn't be where I am today if I hadn't discovered Bliss at the age of 12. Next, we saw the process of social and educational integration starting to take hold in the early 80s. With it, the whole social picture slowly changed. Now we are seeing persons with disabilities taking larger and more active roles in their world. Going along with all of this is the enormous and seemingly endless growth of technology. It is just a few short years ago that I got my first computer. It operated with a tape drive. Now, I have a device on my computer that allows me to make my own CDs!

The internet has also changed how we live and communicate today. We are living in a world of instant communication. It is a time of faxes, of e-mails, of websites, of doing "e-business" across the web. For anyone, who like myself, is blessed enough to be able to take advantage of this 'world changing technology', the benefits seem endless. There is no doubt that e-mail and the web have the potential to be the great equalizer for many nonspeaking individuals.

Over the past years, we have also made progress in narrowing the gap between those who have disabilities and those who don't. In doing this, however, we have created new problems and I personally don't see these issues going away. Certainly we have made great inroads into breaking down all type of barriers. But it seems to have left us with still more questions. How can we take advantage of the increased freedom and independence that society has provided when

funding never stays the same? Some of us have started programs that gave us hope and self-worth in a time where funding was available only to be devastated when the resources ran out. The result was that many individuals ended up worse off than they were before.

In my writings over the years, I have tried to take a philosophical perspective of various issues, first as they impact on the individual and then as they impact on the environment around the person. I have always tried to give you a small spark of hope through reading my columns. If I and my co-Associate Editors have managed to accomplish this, then I know we would feel that our efforts have been worthwhile.

#### Peace of Mind

As I personally take stock of my life over the past two decades, it has been quite amazing. When I was growing up I lived on my family's farm. There I always felt wanted and I hoped that I would be able to stay there and farm the rest of my life. The farm was where rest took place, where my soul was at peace. At least, that is what I thought at the time.

I can remember lots of times, coming home from school or other places feeling the heaviness of constantly having to cope with my disability. Many of those times, my dad would say "Come on Paul, let's go and do something at the back of the farm". As I fought through my teenage years, seeing those fields, and feeling that sun and wind gave me the breathing space I needed to renew my inner strength. At twenty, the waves in my life got so much bigger that not even the farm environment could restore my strength. Eventually, a depression set in that lasted for months. When I finally came out of it, I was given the greatest gift of



my life, a gift that I pray will last until I go home and meet my Lord. The gift has nothing to do with material things. It was the gift that I needed most — the gift of faith. God hasn't and will never block the stormy waters from hitting hard upon me. For many years now, I have been finding out that it isn't me who is driving this ship of mine. It is my Heavenly Father.

## Getting Involved

Two years before I came on the board of editors of **Communicating Together**, I went to my first ISAAC conference which was held in Stockholm, Sweden. It was my first trip overseas. Up to that point, my only involvement in AAC was as a consumer. I had no interest or desire to make AAC my life-long vocation. Sure, I was nonspeaking but I wanted to go in another direction with my life. I had started to edge towards working with street youth as a volunteer. I thought I had the best of two worlds. I could go into Toronto and work in an inner city mission. And I also had the farm to go back to. Life was pretty good and fairly on track. At least, I thought so. I don't exactly know how, but slowly I got more and more involved in the AAC field. I found myself sitting on committees and taking part in meetings. I found myself looking out of boardroom windows wishing and dreaming of the time when I could return home to the farm.

I can almost pin point exactly when the decision was made for me to make AAC and the field of disability in general my lifelong passion. I was offered a full time job at the mission. I really struggled for a couple of weeks trying to decide. The mission job offered an amazing opportunity, one which I never expected. I also knew, however, the burnout rate at that type of job was very high. Plus, I knew that if I took the job, I would have to move to Toronto. So I decided that this wasn't the right job for me.

Soon after that, I found myself at another decision point. I was offered a part-time opportunity at the Hugh MacMillan Centre, now named Bloorview MacMillan Centre. This time, the job was as a research assistant in their Microcomputer Applications Program (MAP). By agreeing to take this position, I was thrown into the world of research and disability.

During these twenty years, I have also moved from learning Bliss into the enormous and exciting world of literacy and writing. This process was slow, taking over twenty years before I really felt comfortable working in the world of text. It is funny. One of my childhood dreams was to be a writer even though at the time, the printed word was like a foreign land to me.

Now I sit on many committees and boards. I no longer sit in meetings half heartedly, distracted. I no longer have the farm environment either as my refuge. We just couldn't keep it up and had to sell it. On the other hand, I have been overseas five times, three of which were to attend ISAAC conferences in Sweden, Holland and Ireland. The other two times I was extremely blessed to have the opportunity to be involved with some AAC awareness activities in Israel and South Africa. The personal growth that I gained on these trips was immeasurable. These changed my life. It was this series of events that forced me to realize that my calling was to work in the field of AAC and the huge world of educating the general public about disabilities.

## Overcoming Barriers

Over the last twenty years, society has also seen many new ideas that have dramatically changed how we live, play and work. Although many of these new technologies and inventions were designed primarily to help the general population, they also helped to break down many barriers for persons with disabilities. Some-

times however, these new developments inadvertently added to the barriers that already existed or created new ones. I am convinced however, that the greatest barriers that we must battle against are the barriers within us. Furthermore, even though things like technology are constantly changing the environment in which we live, many of the major issues the person with a disability must deal with remain the same. These are the basic issues of the human struggle:

- Who am I as a nonspeaking person?
- How will I fit into a society that views me as a "half person"?
- How do I overcome the views of the world that just doesn't accept me?
- Will I ever be at peace with my life?

While we often feel that others should adapt to us or just accept us the way we are, we also have a responsibility. We are responsible for making it easy for individuals to get to know us. When it comes to having the opportunity to live life equally with others, I agree that, in general, people with disabilities are not being treated fairly. There is no question that the environment in which I live plays a crucial part in terms of empowering or disempowering me. Whether we are considered to be "normal" or "disabled", I deeply believe that the real battle to be fought and won is not on the outside. It is on the inside. It is who I am within myself that allows life to be meaningful or meaningless.

For my final comments, I would like to share with you an article that I wrote this summer for a local newspaper. It is called "*It takes someone special to foster 'soul smiles'*". I hope producing "soul smiles" is the goal of all of our activities in all areas of our lives. God be with you all.



## Soul Smiles

As I sit back in my chair, I watch the faces of the musical group preparing to play. I can see they are talking quietly to themselves as they gaze out into the crowd. All their preparations have been for this one evening. Possibly some of them lay awake last night, practising each beat of each song. As they got dressed in their finest, I am sure excitement surged up in the soul of each musician. The special night is finally here!

I especially remember one part of a song they performed. It was "how long can we survive before we are set free?" I am sure these words went unnoticed to many when the song was being played, but to me this was the crucial message of the night. The name of this group was *Ann's Musical Friends*. You possibly won't ever hear them. They won't be in any great music hall, coming near you. They aren't or will never be well known in musicians' circles, but they are loved, accepted by all who really know them and they are respected as individuals. Their beats were maybe a little off, and when they tried to sing, the words didn't come, because most of them were nonspeaking. When I really looked and really listened to the music from each soul, however, I knew that each of them was a musician. They just had to live within bodies in which there was no way to foster or follow normal musical activities. If smiles could sing, believe me, the singing would be amazing from this group of severely physically disabled adults.

I was reminded again how important it is for each of us to have an escape path in our life, just to spread our wings and enjoy being a kid at heart. My brother bought a dune buggy. He didn't really need it at all. When he gave me a ride, I saw that same smile that I saw on my friends' faces at the musical. These smiles are "soul smiles". They are crucial to have in our lives. They come from a host of

activities that are individualized and suited to each of us.

It is impossible to put into words the heartbreaks that anyone who has a severe disability goes through in life. I am tagged as having a disability myself, but I am fairly independent. I am too often discouraged at how some in our society treat any person with severe disabilities. Being human means reacting to others. Our lives are dependent on human interaction and relating to our fellow man. We aren't ships unto ourselves, making solo trips across the sea of life. We are a by-product of our interactions with others.

It is my conviction that we don't assume anything when meeting a person who doesn't measure up to the social "norms". There is nothing more beneficial to an individual than to be treated with dignity and honour. At the same time, there is nothing more disempowering than a person being deprived of this treatment. Two old sayings come to mind here, "You can't judge a book by its cover," and "Treat people as you want to be treated yourself." The mistreatment of those with disabilities that goes on daily, I am sure, would blow us away.

When it comes to hiring persons to help in caring for others, we must be aware of the potential for mistreatment in the form of physical and psychological neglect and abuse. We must have high standards. Adequate resources are needed for ongoing training and retraining. It is very important to be observant and attentive to the physical and mental needs when caring for others. These jobs aren't for everyone. It takes a very special person. If a person is not doing the job in a manner that gives dignity and self-worth to the people in her/his care, then this person's role should be reviewed and steps taken. Care workers can become wrapped up in following guidelines and rules that have been established to meet budget

requirements, not to meet the needs of those being served.

If any of these guidelines and rules stand between preserving human life and honouring it, then the red lights should be on, folks. When we put finances ahead of personal safety and personal growth, the yellow lights should be flashing. I ask you, how long can those with severe disabilities survive before we set them free? As the more physically able members of our communities, we hold the keys that can and will give freedom. Some of these keys are physical but the keys that I am talking about here are the mental keys of:

- *honouring human life,*
- *seeing all people as equal,*
- *building up others, and*
- *having high regard for all persons' hopes, dreams, needs and wants.*

I think one of the most delightful gifts I was allowed to receive this spring was when I attended that musical event and met Megan, the young music therapist who made it all happen. She is a delightful young woman who will go far, not only because she is totally immersed and committed to the music of a particular night and to her interactions with her students with physical disabilities, but because she actually pulls out "soul smiles." At the same time, she gives her students a new reason to live. Megan has been trained as a music therapist, but I know that her compassion and humanitarian skills don't all come from her schooling. Quite likely she learned it from a non-funded source like her family and/or peers. There are many Megans out there. They are the very special individuals in our world, doing what they do best, fostering and producing "soul smiles" in others. I personally thank all those like her. Oh that we all might model her example.



# CONTENTS

## EDITORIAL

- 2 Teaching & Learning over the Past Eighteen Years

TRACY SHEPHERD &  
COLLEEN McGAFFEY

- 3 Today: A Poem in Blissymbolics

RUSSELL SECHINI &  
TREENA GUY

## FEATURE

- 4 Sharing Ideas with Nora

NORA ROTHSCILD

## TEACHING AND LEARNING

- 9 On the Teaching Platform

TRACY SHEPHERD

## PERSPECTIVES

- 15 Chase Your Dreams: Guidelines for Getting . . .

VICTOR VALENTIC

## PERSPECTIVES

- 18 Decisions and Commitments: Then and Now

JUDY SELIGMAN-WINE

## PAUL'S PULPIT

- 21 Reflections Over the Past Eighteen Years

PAUL MARSHALL

**Communicating Together** was established in 1982 and has been published quarterly since 1991 by *Sharing to Learn*. Beginning in 1997, it is available both in hard copy and as **ComTog-Online**. The magazine's mandate is to provide a means of sharing the life experiences and communication accomplishments and challenges of augmentative communicators. Its readership includes augmentative communicators, friends, assistants and supporters and all members of the community who wish to know more about those who use augmentative and alternative communication (AAC).

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Our cover for this issue shows Megan Gibson, a musical therapist, playing at an *Evening of Music with Anne's Musical Friends* (a group started by Anne Running). Megan is the model of someone who frequently exhibits one of Paul's *Soul Smiles*.

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